

2022-2023

FISCAL YEAR JULY 1, 2022 – JUNE 30, 2023

ANNUAL REPORT



spinalcsf leak
FOUNDA T I O N
because your dura matters®



a year's overview

LETTER FROM THE EXECUTIVE DIRECTOR

Our 2022–2023 year has been one marked by both exciting progress and devastating loss. In July of 2022, we welcomed three new members to our Board of Directors, and just a few months later we sent out the first survey from our new Advocacy team. In November of 2022, a project years in the making came to fruition as we published our long-awaited physician directory.

But in January 2023, we were devastated by the unexpected passing of board member Amanda J. Pickard, PhD. Dr. Pickard, who held a PhD in chemistry and worked as a research scientist, was beloved by so many in our spinal CSF leak community, and we mourned as both coworkers and friends. Her spinal CSF leak story was complex, thorny with adjacent diagnoses and branching complications. But no matter what point she was at in her own journey, she was able to rally others with her fighting spirit. She shared advice and connected people to resources, she offered practical help and emotional understanding, she worked hard to assist other patients, and she was an encouraging, awe-inspiring role model for persistence in the face of adversity.

In the face of this loss, we committed ourselves to the work she believed in so strongly—continuing to educate physicians about spinal CSF leak, connecting with other organizations to help advocate for people with headache disorders, and creating inclusive, thoughtful campaigns to reflect the experiences of people in our community. As we begin a new fiscal year, with so many of the projects meaningful to Dr. Pickard finally starting to come to fruition, we look forward to honoring her memory in the work we do to make a meaningful difference in the lives of all those affected by spinal CSF leak.

Andrea J. Buchanan, Executive Director

annual report

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annual report

EXECUTIVE SUMMARY

The Spinal CSF Leak Foundation was established as a 501(c)3 non-profit organization in 2014 by individuals affected by spinal cerebrospinal fluid (CSF) leak. Our mission is to reduce the suffering of persons affected by intracranial hypotension or spinal CSF leak. We do this through education and awareness-raising, community support and advocacy, and the funding of research.

All of our board members and our Executive Director are either currently or formerly affected by this disorder, and several remain moderately to profoundly disabled. Our Medical Advisory Board is composed of a diverse group of physicians, all of whom are expert in understanding spinal CSF leak. Our teams include board members and volunteers, all of whom are affected by the disorder in some way and therefore invested in our mission.

Our program categories are (1) education and awareness; (2) research; and (3) community support and advocacy

Education and awareness. We have garnered a reputation as the leading voice for up-to-date and reliable information for both laypersons and medical professionals. We co-direct an annual symposium in partnership with a major academic institution that brings together clinician experts, patients, and caregivers. Additional medical professional conferences are supported through planning and/or grant support. The power of storytelling is harnessed in both narrative and video formats. Our annual awareness week (leakweek) and virtual activity challenge (duradash®) effectively engage our patient community and beyond.

Research. Since its inception, the Spinal CSF Leak Foundation has been a leader in fostering collaborative efforts in education, awareness, and research around this disorder. Our medical advisory board is a strong, diverse, multidisciplinary, multi-institutional group of specialists that is engaged in both educational and research-oriented activities. We worked with stakeholders to create—and successfully implement—relevant ICD-10 codes so that spontaneous intracranial hypotension (SIH) due to spinal CSF leak could be properly coded and billed, thus facilitating research including essential epidemiological

annual report

EXECUTIVE SUMMARY

studies and access to care. For several years we have provided grants of \$5,000 to \$50,000 to researchers, one of which has led to a larger NIH-funded project. In 2021, we established our first patient advisory panel for research, and we are currently working with clinicians, researchers, and patients to building the infrastructure for a patient registry and collaborative research network, all to accelerate advances in this field and improve patient outcomes. Our medical advisory board continues to collaborate with an international multidisciplinary team to develop needed diagnostic and treatment guidelines. And in 2021, we were awarded a one-time operating grant from the Chan-Zuckerberg Institute in support of our work.

Community Support and Advocacy. High-quality compassionate informational and emotional support is essential for people affected by spinal CSF leak. We partner with Inspire as our support community, and we network with other organizations representing related disorders to make our advocacy efforts even more effective.

Our mission drives our specific activities within each program category. Over the next year and beyond, we plan to build upon our successes, broadening our efforts in education, research, and advocacy such that persons affected by intracranial hypotension or spinal CSF leak will experience shorter diagnostic delays, receive more timely and appropriate diagnostic testing and treatments, and have better long-term outcomes.

an overview

ABOUT SPINAL CSF LEAK

Spinal cerebrospinal fluid (CSF) leak is an important and underdiagnosed cause of new-onset headache. The brain and spinal cord are bathed in fluid known as cerebrospinal fluid (CSF) in one continuous compartment. This fluid is held inside by a tough layer of connective tissue surrounding the brain and spinal cord called the dura mater. When the spinal dura mater has a hole, tear, or other defect, CSF can leak out of this compartment. These defects, whether small or large, can result in a low volume of CSF remaining around the brain and spinal cord. It is this loss of CSF volume that affects the brain and spinal cord in a number of ways.

While there are many symptoms, the most common is head pain that is worse after minutes to hours upright and improved when lying flat, or head pain that is less obviously positional but gets worse as the day goes on. Most of the time, this is mistakenly assumed to be a migraine headache, or is attributed to another cause. Many patients are quite disabled by their limited functional upright time each day. Very rarely, this condition can be life-threatening.

Spinal CSF leak is a diagnosis that tends to be missed when it occurs spontaneously, while cases that arise after medical procedures like spinal taps and spinal surgery are usually recognized more quickly. Spontaneous spinal CSF leaks have known associations with underlying heritable disorders of connective tissue and/or bone spurs along the spine.

Because awareness remains low among health professionals and because there is considerable variability in the symptom patterns and complications, spinal CSF leak can be challenging to diagnose. The diagnosis is suspected based on symptoms and evaluated with imaging of the brain and spine.

Treatments include spinal injection procedures and surgery. With the correct diagnosis and treatment, the prognosis is generally good, but an improved quality of life remains elusive for many patients due to the limitations of current imaging and treatments. There is much that remains unknown about the incidence and prevalence, underlying causes of spinal CSF leak, and about CSF dynamics, complications, and long-term outcomes.

the foundation's

ORGANIZATIONAL PROFILE

Spinal CSF Leak Foundation has an Executive Director, a Board of Directors, and a Medical Advisory Board. Each member of the Board of Directors supports the work of Spinal CSF Leak Foundation to provide mission-based leadership and strategic governance. Board members serve a one-year term and are eligible to be reappointed for successive terms. Medical Advisory Board members serve two-year terms and are eligible for reappointment for successive terms.

The Foundation operates with just one paid staff member and limited contract help, and is powered primarily by volunteers.

Board of Directors

July 1, 2022 through June 30, 2023

Martha Bond

Jodi Ettenberg

Megan Kocher

Jen MacKenzie

Two board members with significant disability due to spinal CSF leak wish to remain anonymous.

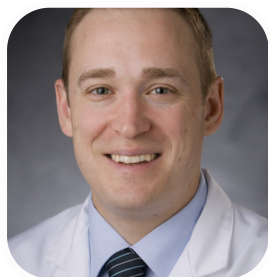
Executive Director

Andrea J. Buchanan.

the foundation's

ORGANIZATIONAL PROFILE

Medical Advisory Board July 1, 2022 through June 30, 2023



Timothy J. Amrhein, MD

Associate Professor
Director of Spine Intervention
Department of Radiology
Duke University Medical Center,
Durham, NC



David Dodick, MD

Professor of Neurology
Medical Director of Headache Program
Medical Director of Sport Neurology and
Concussion Program
Mayo Clinic, Scottsdale, AZ
Past President, American Headache Society
Past President, International Headache Society



Ian Carroll, MD, MS

Associate Professor of Anesthesiology,
Perioperative and Pain Medicine
Stanford Headache Clinic
Stanford University School of
Medicine, Redwood City, CA



Deborah Friedman, MD, MPH

Neuro-Ophthalmologist and Headache
Medicine Specialist
Dallas, Texas



Jeremy Cutsforth-Gregory, MD

Assistant Professor of Neurology
Department of Neurology
Mayo Clinic, Rochester, MN



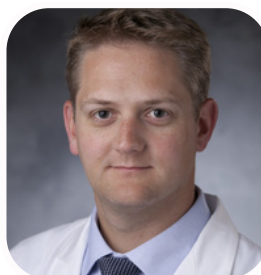
Linda Gray Leithe, MD

Associate Professor
Division of Neuroradiology
Department of Radiology
Duke University Medical Center,
Durham, NC



Connie Deline, MD

Founder, Spinal CSF Leak
Foundation
Camp Hill, PA



Peter G. Kranz, MD

Associate Professor
Chief, Neuroradiology Division
Department of Radiology
Duke University Medical Center,
Durham, NC

the foundation's

ORGANIZATIONAL PROFILE

Medical Advisory Board July 1, 2022 through June 30, 2023



Charles Louy, PhD, MD, MBA

Anesthesiologist
Los Angeles, CA



Jill Rau, MD, PhD

Neurologist- Headache Specialist
HonorHealth Neuroscience
Institute, Scottsdale, AZ
Chair, Special Interest Group on
CSF Pressure Disorders, American
Headache Society



M. Marcel Maya, MD

Co-chair, Department of Imaging
S. Mark Taper Foundation Imaging
Center
Cedars-Sinai, Los Angeles, CA



Wouter I. Schievink, MD

Professor of Neurosurgery
Director, Cerebrospinal Fluid Leak Program
Director, Vascular Neurosurgery Program
Cedars-Sinai, Los Angeles, CA



Abhay Moghekar, MBBS

Associate Professor of Neurology,
Otolaryngology and Neurosurgery
Research Director, Center for
CSF Disorders
Johns Hopkins, Baltimore, MD



Stephen Silberstein, MD

Professor of Neurology
Director, Jefferson Headache Center
Thomas Jefferson University,
Philadelphia, PA
Past President, American Headache Society



Simy Parikh, MD

Assistant Professor of Neurology
Jefferson Headache Center
Thomas Jefferson University,
Philadelphia, PA

Our mission is to reduce the suffering of persons affected by intracranial hypotension or spinal cerebrospinal fluid leak.

MISSION, VISION, VALUES, & GOALS

our vision

Our vision is for each person affected by intracranial hypotension or spinal cerebrospinal fluid leak to receive prompt diagnosis, access to appropriate testing and treatments, and a favorable outcome.

our values: compassion, integrity, inclusiveness, hopefulness

Our compassion for affected individuals fuels our efforts, and everything we do, we aim to do with the utmost integrity. We honor and respect the diversity of our community. And we maintain hope for the future despite the challenges.

our goals

Elevate awareness

We seek to raise the level of awareness of spinal CSF leak among laypersons and health professionals.

Educate

We support and provide professional education on all clinical aspects of spinal CSF leak.

Support

We provide each person affected by spinal CSF leak access to compassionate, high-quality informational and emotional support.

Advocate

We contribute our voice in advocating for better access to care and better support systems.

Connect

We promote collaborations among all stakeholders to accelerate advances.

Research

We encourage and support research on the epidemiology, causes, diagnostic testing, treatments, complications, and outcomes of spinal CSF leak.



our programs

EDUCATION & AWARENESS

our website and social media

More than 92,000 people visited our website during fiscal year 2022-2023. Roughly 57,000 of those people were located in the US, but our site attracts visitors from around the world, including the UK, Canada, Australia, India, Ireland, Germany, China, New Zealand, and Sweden. In addition to sharing information on our website, we also regularly update our community via a monthly email newsletter.

With our nearly 10,000 Facebook followers and 2,000 Instagram followers, our social media posts were able to reach over 100,000 people on Facebook and nearly 11,000 people on Instagram. Our YouTube channel of 100 videos has been viewed over 640,000 times for a total of almost 75,000 hours of watch time. That's a lot of spinal CSF leak awareness!

storytelling: patient storytellers

Our library of video and narrative format patient stories continues to grow, featuring 24 video stories and 19 narrative stories. Our continued goal is for the diversity of patient stories to reflect the broad range of affected individuals, clinical presentations, clinical courses, and outcomes.

our programs

EDUCATION & AWARENESS

storytelling: spotlights

These brief features published in conjunction with awareness events allow us to share small glimpses of the lives of those in our community.

Raising awareness is one of the most important things we do. From the new ICD-10 codes we helped implement, to the educational resources and videos we share, to the symposia and conferences we support—all of this helps more people understand our condition, and helps physicians learn more about how to recognize, diagnose, and treat spinal CSF leak. During #GivingTuesday, we invited patients and physicians to share what they want each other to know about spinal CSF leak.

During the week leading up to Mother's Day, our “Tough Mother” spotlight featured stories from [Ryne](#), [Shannon](#), [Jennifer](#), [Laurie](#), [Laura](#), [Anne](#), and [Jane](#)—all mothers in our community—about what it's like to parent while living with a spinal CSF leak. Their experiences of grappling with uncertainty, grief, and resiliency as they navigate illness and parenthood illuminated how learning to be vulnerable, flexible, and creative honors the “tough mother” in all of us.

And during #duradash, over the course of the two-week event select, we invited participants to share their experiences with spinal CSF leak, their hopes for future research, and how they embrace our theme of "start where you are." (See their spotlights here: [Samantha](#) and [Allison](#).)



I wish that every doctor had information at their fingertips regarding spontaneous spinal CSF leaks.



Diana, spinal CSF leak patient

Seeing my patients' smiles and tears after informing them we found their previously undetected spinal CSF leak is one of my greatest joys as a physician.

Dr. Mark Mamlouk



“IT'S VERY HARD FOR CHILDREN TO UNDERSTAND AT SUCH A YOUNG AGE. SHE DOESN'T REMEMBER ME AS ANYTHING BUT FLAT ON MY BACK IN BED.”

—LAURA, MOTHER OF ONE



I want people to know that even if blood patches fail and your leak does not show on imaging, you can still have a spinal CSF leak.

#duradash participant Samantha Gosser

our programs

EDUCATION & AWARENESS

storytelling: ADAPT

For those living with pain, chronic illness, or a condition like spinal CSF leak, it can be particularly difficult to talk about mental health, as patients sometimes run the risk of having their emotional challenges interpreted as a cause of—rather than a reaction to living with—their condition. However, we know that coping with a spinal CSF leak is a singular experience that profoundly affects quality of life and emotional well-being.

In 2022, we invited Jodi Blaszyk, PsyD, a spinal CSF leak patient and clinical psychologist, to share a mental health concept she coined for support in living with spinal CSF leak called ADAPT. Her series of articles, each expounding on a different letter in the acronym, explored the grief and pain of coping with a spinal CSF leak—and also offered a path towards radical acceptance, compassion, and finding small moments in which to thrive. The core concepts embedded in the acronym ADAPT are Acceptance, Diagnosis, Advocate and educate, Plan, and Thrive. However, these aren't stages that a person experiences linearly, but rather ideas that can help us attend to our mental well-being at any time during the process of living with a spinal CSF leak. For this year's May 2023 Mental Health Awareness Month, Dr. Blaszyk reflected and revisited what it has meant for her, personally, to use ADAPT in her life over the past year as she journeyed through diagnosis and treatment.



My Year of
Adaptation:
What I
Learned
Putting
ADAPT
into Action



our programs

EDUCATION & AWARENESS

duradash® 2023: start where you are

This year's duradash®, which took place May 28 - June 10, was a two-week virtual activity challenge to raise awareness about spinal CSF leak. For people living with spinal CSF leak, being upright at all is a challenge, and that's why our theme of "start where you are" is so important. When you start where you are, every activity counts, whether it's reading in bed or going for a walk.

The #duradash goal for participants was to do 150 minutes of any activity, anytime between May 28 - June 10—but exactly what to do and when to do it was up to them. As our instructional materials put it, "Any movement or activity that is appropriate for your current state of health counts towards your #duradash goal. That includes anything from meditation to relaxation, self-care, gardening, sitting,

standing, tai chi, walking, biking, hiking, or even running, if that's appropriate for you—and any other kind of "everyday life" activity you might do in the course of a day. (Yes, showering counts!)"

Participants were encouraged to raise funds through their campaigns in order to enable the Foundation to continue to raise awareness among medical professionals and others through

education and research that specifically advances the understanding, diagnosis, and treatment of intracranial hypotension and spinal CSF leak.

This year, our duradashers spent over 7,000 minutes and raised nearly \$15,000 to educate others about spinal CSF leak and raise crucial funds for continuing awareness, education, and research. From young people who streamed video games, to older people who went on 20-mile walks, to others who knit or crocheted or did macrame, to still others who colored or shared facts and information on social media while flat—everyone did an amazing job of making this year's #duradash a success!

***In the end, our community
logged roughly 7,000
minutes of activity and
raised almost \$15,000!***

our programs

EDUCATION & AWARENESS

duradash® 2023: start where you are

To help people share the news about #duradash and leakweek, we created a #duradash toolkit with everything from event graphics and information about spinal CSF leak and the Foundation, to customizable templates for people to use whether sending email, posting on social media, or texting their family and friends about it. We worked with a group of volunteers, giving them early access to the toolkit and our #duradash platform, so that they could begin to get the word out about the event and start getting people excited to participate. And of course we created #duradash t-shirts!

We also created a [video overview](#) of what #duradash was all about, to help participants and donors understand the importance of raising awareness and funds, and what we hoped to accomplish. And we partnered with CauseVox again, to give our participants a platform that's easy to use and mobile-friendly—which is very important to our community, as many are unable to be upright at a computer.

Finally, we capped off #duradash with a social media [awards ceremony](#). Everyone who participated was honored with an award of some kind, from the “Start Where You Are” award to the “Because You Matter” award, to an “Excellence in Owl Artistry” award ([you'll have to see it to understand](#)), and awards for the most funds raised by an individual and by a team.



our programs

EDUCATION & AWARENESS

leakweek 2023

This year's awareness week, #leakweek2023, took place June 4–10, 2023. All throughout leakweek, we shared information about spinal CSF leak to help more patients living with this under-diagnosed and disabling neurologic disorder receive correct and timely diagnosis and treatment. Once again, we were thrilled to team up with Spinal CSF Leak Canada and the CSF Leak Association in the UK to make leakweek truly international.

We announced our partnership with NORD in creating a spinal CSF leak patient registry. NORD is an independent nonprofit that built its IAMRARE® online registry platform as part of its mission to help identify and treat all 7,000 rare diseases. Spinal CSF Leak Foundation is a member of NORD, and our organizations will work together to understand the challenges and identify opportunities to advance research for this rare disease patient population. We anticipate that the registry we build using the IAMRARE® platform will be ready to launch next spring.

We also worked with the CSF Leak Association and Spinal CSF Leak Canada to create co-branded informational resource documents and fact sheets to help raise awareness, and gave updates on Foundation-funded research. Our international collaboration again worked to emphasize that awareness, education, and research are global issues that all three of our organizations are passionate about addressing.

What is a spinal CSF leak?

Cerebrospinal fluid (CSF) is a clear, colorless liquid that bathes and supports the brain and spinal cord. This fluid is held in place by a tough membrane called the dura mater.

When there is a hole, tear, or defect in the dura mater along the spine, CSF can escape, causing a loss of CSF volume. This is known as a spinal CSF leak.

A spinal CSF leak is a highly disabling and often invisible disorder. Patients can suffer for months or even years with the wrong diagnosis and treatments.

© Spinal CSF Leak Foundation

We are proud to announce the development of a

Spinal CSF Leak Patient Registry

In partnership with NORD®

Quality of Life in Patients with Confirmed and Suspected Spinal Cerebrospinal Fluid Leaks

Poster: Dr. Deborah Friedman's study on Quality of Life in Patients with Confirmed or Suspected Spinal Cerebrospinal Fluid Leaks

Background: Spontaneous intracranial hypotension (SIH) is a debilitating condition that occurs with spinal cerebrospinal fluid (CSF) leaks. SIH is most associated with profound headache that wakes upright time and mobility. It is often difficult to diagnose and treat, and severely affecting patients' quality of life (QoL).

Methods: Currently, the extent of SIH on QoL is understudied. Therefore, we sought to document the relationship between SIH and a wide range of QoL measures, as well as differences by diagnosis and treatment status.

Results: The cohort had an average age of 51.1 years (SD: 13.8) and was predominantly female (88.5%). Caucasian (51.8%) and married (58.2%). 59 participants (82.7%) indicated a confirmed diagnosis, and 13 (17.8%) were suspected.

Discussion: 74.3% scored within the most severe headache category on the NRS. 48.3% scored in the moderate depression range or worse (+10). 25.4% scored for moderate or worse anxiety (+10). Of the 67 CSFQSIQ respondents, 64.2% had previously endorsed a wish to be dead and 23.6% had previously endorsed suicidal behavior. Participants with confirmed and suspected diagnosis had similar QoL outcomes.

Conclusion: SIH is associated with severe headache pain and high rates of depression, anxiety, and suicidality. Improved identification and treatment of SIH are imperative to improve patients' QoL.

Acknowledgments/Funding: We are grateful to the Spinal CSF Leak Foundation for their support and funding of this project.

References: Friedman DJ. Headaches Due to Low and High Intracranial Pressure. *Clinical Neurophysiology*. 2018;129(10):1988-1993. doi:10.1016/j.clinph.2018.08.005. Cheema S, Jay C, Pugh A, Grewal-Burni J, Theopelis T, Williams M. Spinal CSF Leak: A Review of the Literature. *International Journal of Spinal Cord Injury*. 2019;16(1):1-10. doi:10.1080/15368352.2019.1611151. Z'Angola L, Jones-Mogkley M, Vestberg A, et al. Clinical Presentation, Diagnostic Methods, and Management of Spontaneous Intracranial Hypotension: A Systematic Review and Meta-analysis. *Headache*. 2021;61(10):1482-1491. doi:10.1111/head.14579.

our programs

EDUCATION & AWARENESS

leakweek 2023: the view from here

Several months before leakweek, as part of Mental Health Awareness Month in North America and Mental Health Awareness Week in the UK, the Spinal CSF Leak Foundation, Spinal CSF Leak Canada, and the CSF Leak Association partnered to raise awareness about the mental health impacts of spinal CSF leak by making the invisible visible.

#TheViewFromHere project aimed to illustrate and share what life is like with a spinal CSF leak from the point of view of those who live with one. We invited people to participate by taking a photo of what they see as a person with a spinal CSF leak.

The final project debuted during leakweek and ultimately featured over 30 submissions from patients in seven different countries in a powerful video exploring the reality of spinal CSF leak and how it affects our lives and quality of life.

#theviewfromhere

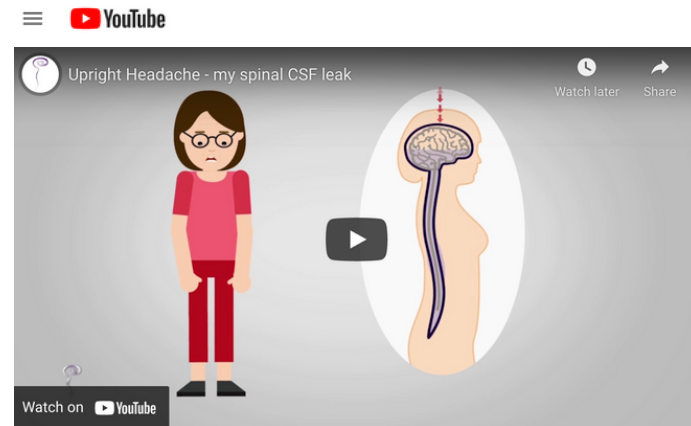


our programs

EDUCATION & AWARENESS

explainer videos

Our animated video on “Upright Headache,” which we produced in 2017, has now been viewed over 113,000 times. Additional explainer videos are being planned.



Upright Headache - my spinal CSF leak

medical education

We support intracranial hypotension medical education with planning support, promotion, and/or educational grants. In 2023, for the fifth year in a row, we provided an educational grant to the annual Cedars-Sinai Intracranial Hypotension Conference. We also provided support to the SIH Naples Conference.



2023 INTRACRANIAL HYPOTENSION CONFERENCE



our programs

RESEARCH

spontaneous intracranial hypotensions guidelines project

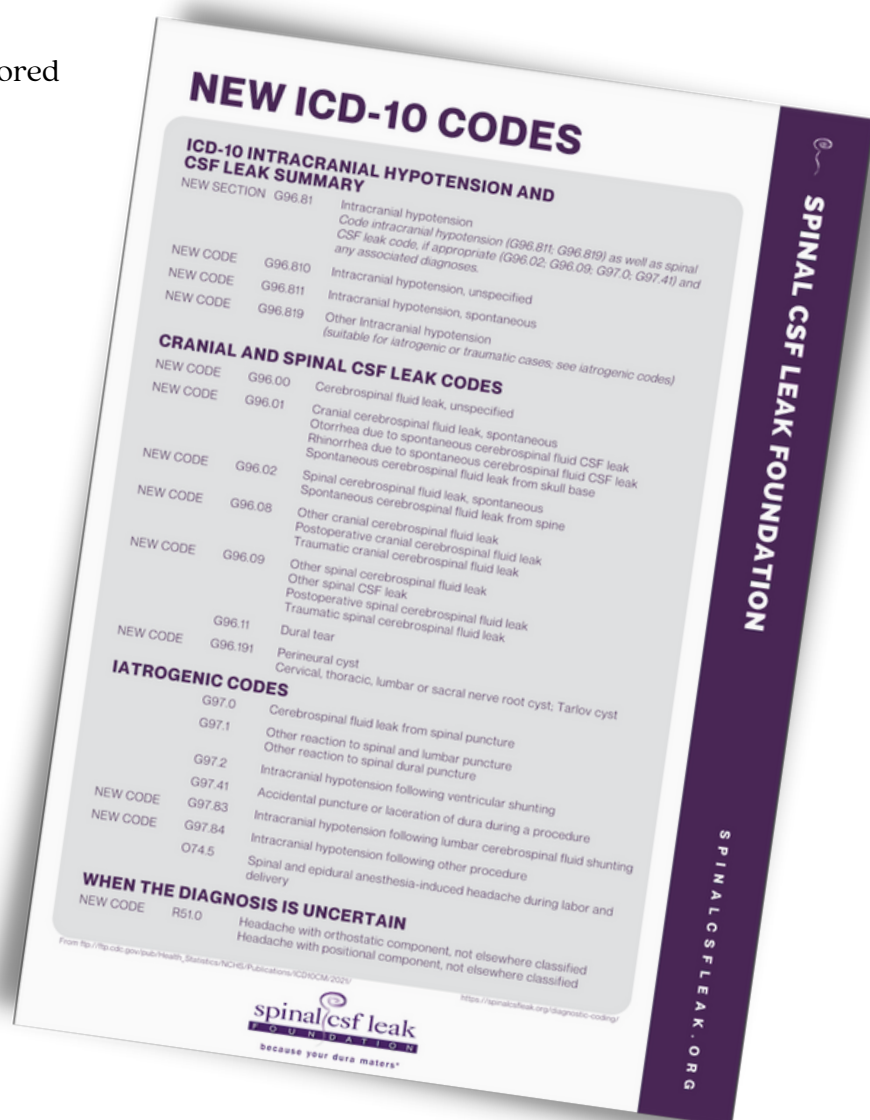
This ambitious project was initiated by medical advisors Dr. Connie Deline and Dr. Stephen Silberstein, under the umbrella of the American Headache Society, and is still ongoing. The panelists on this project represent several academic institutions and subspecialties including primary care, headache neurology, general neurology, neuroradiology, neuro-ophthalmology, anesthesiology, neurosurgery, and genetics.

rare disease database report

This summary, updated in 2020, was co-authored by Dr. Connie Deline and is an [excellent introduction to and overview of spontaneous intracranial hypotension](#).

ICD-10 coding proposal

Thanks to sustained effort by the Spinal CSF Leak Foundation in collaboration with our medical advisory board and a team of key opinion leaders, the ICD-10 Coordination and Maintenance Committee approved proposed our new and revised codes related to intracranial hypotension and CSF leaks. These codes spearheaded by the Foundation were implemented on October 1, 2020, in the United States. This is critical for accuracy of medical records, insurance reimbursement of testing and treatments, disability benefits, and research. [A summary of these codes is available here.](#)



our programs

RESEARCH

research grants

To date, we have awarded six research grants. Several of our previously funded studies are nearing completion and/or publication. You can read about these Foundation-funded research updates [here](#).

The Spinal CSF Leak Foundation's most recent grant of \$50,000 was awarded to fund a groundbreaking research project from Dr. Deborah Friedman on quality of life in spontaneous intracranial hypotension. This study is now completed and is nearing publication.

Quality of Life in Patients with Confirmed and Suspected Spinal Cerebrospinal Fluid Leaks

Victor Liaw BS¹, Morgan McCreary, PhD², Deborah I. Friedman, MD, MPH²
¹University of Texas Southwestern Medical School, ²Department of Neurology, University of Texas Southwestern Medical Center

UTSouthwestern
Medical Center

Background

Spontaneous intracranial hypotension (SIH) is a debilitating condition that occurs with spinal cerebrospinal fluid (CSF) leaks. SIH is most associated with orthostatic headache that limits upright time and mobility. It is often difficult to diagnose and treat, profoundly affecting patients' quality-of-life (QoL).

Currently, the impact of SIH on QoL is understudied. Therefore, we sought to document the relationship between SIH and a wide range of QoL measures, as well as differences by diagnosis and treatment status.

Methods

We conducted a cross-sectional survey of patients with confirmed or clinically suspected SIH evaluated from 2016 to 2022. Participants completed the following validated measurements online (REDCap V 11.2.2): SF-36 (general well-being), PHQ-9 (depression), GAD-7 (anxiety), FACT-Sp-12 (spinal well-being) and HIT-6 (headache impact). Subsequently, willing participants were interviewed to administer the C-SSRS assessing suicidal behavior and ideation.

Results

Demographics

The cohort had an average age of 51.1 years (SD: 15.5) and was predominantly female (89.5%). Caucasian (91.8%), and married (89.5%). 59 participants (62.1%) indicated a confirmed diagnosis, and 73 (76.8%) were symptomatic.

Quality of Life Outcomes

Discussion

- 74.5% scored within the most severe headache category on the HIT-6
- 49.1% scored in the moderate depression range or worse (≥10)
- 25.4% scored for moderate or worse anxiety (≥10)
- Of the 67 C-SSRS respondents, 64.2% had previously endorsed a wish to be dead and 22.4% had previously demonstrated suicidal behavior.
- Symptom-free SIH patients scored significantly better than symptomatic patients
- Participants with confirmed and suspected diagnoses had similar QoL outcomes

Conclusion

SIH is associated with severe headache pain and high rates of depression, anxiety, and suicidality. Improved identification and treatment of SIH are imperative to improve patients' QoL.

Acknowledgements/Funding

We are grateful to the Spinal CSF Leak Foundation for their support and funding of this project.

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Outcomes Stratified by Diagnosis and Symptom Status (Median [Q1-Q3])

	Total Sample (n=85)	Asymptomatic (n=78)	No Symptoms	Confirmed (n=59)	Coef. Est. (95% CI)	p-value
PHQ-9 (Depression)	45 (28-61.8)	40 (28-45)	40 (28-45)	45 (28-61.8)	1.83 (0.33)	0.0004
GAD-7 (Anxiety)	33 (9-50)	33 (9-50)	33 (9-50)	33 (9-50)	0.00 (0.00)	0.9999
HIT-6 (Headache Impact)	37 (5-51.4)	37 (5-51.4)	37 (5-51.4)	37 (5-51.4)	0.00 (0.00)	0.9999
FACT-Sp-12 (Spinal Well-Being)	35 (12-51.5)	35 (12-51.5)	35 (12-51.5)	35 (12-51.5)	0.00 (0.00)	0.9999
SF-36 (General Well-Being)	36 (10-51.5)	36 (10-51.5)	36 (10-51.5)	36 (10-51.5)	0.00 (0.00)	0.9999
PHQ-9 (Depression)	45 (28-61.8)	45 (28-61.8)	45 (28-61.8)	45 (28-61.8)	0.00 (0.00)	0.9999
GAD-7 (Anxiety)	33 (9-50)	33 (9-50)	33 (9-50)	33 (9-50)	0.00 (0.00)	0.9999
HIT-6 (Headache Impact)	37 (5-51.4)	37 (5-51.4)	37 (5-51.4)	37 (5-51.4)	0.00 (0.00)	0.9999
FACT-Sp-12 (Spinal Well-Being)	35 (12-51.5)	35 (12-51.5)	35 (12-51.5)	35 (12-51.5)	0.00 (0.00)	0.9999
SF-36 (General Well-Being)	36 (10-51.5)	36 (10-51.5)	36 (10-51.5)	36 (10-51.5)	0.00 (0.00)	0.9999

Dr. Friedman and her team recently presented a poster with some of their findings. Overall, the study's conclusion was: "SIH is associated with severe headache pain and high rates of depression, anxiety, and suicidality. Improved identification and treatment of SIH are imperative to improve patients' quality of life."

Dr. Friedman notes that, to her knowledge, this study is the first in headache medicine to include a measurement of spirituality in assessment of quality of life.

In Dr. Friedman's study, participants experiencing symptoms of spinal CSF leak scored much worse on this assessment compared to other groups—including people with cancer and AIDS. It's a striking example of just how severely spinal CSF leak can affect a person's well-being.

Funding Dr. Friedman's study means that patients' voices can finally be heard in terms of exactly how disabling this condition is. And ultimately, this information can be used to help speed treatment and further even more research.

our programs

RESEARCH

patient advisory panel for research

We created our Patient Advisory Panel for Research in 2021 as an effective means to formalize the vital role of patients in moving research forward. Inclusion of the patient voice in research is crucial, especially in the context of a rare disease, because no stakeholder can have the constant and relentless drive of the patient searching for cures—and no one other than the patient can better report the patient experience. Having patients and caregivers engaged in setting research priorities, ensuring the relevance of studies, choosing outcomes that matter to patients, developing study design, providing insights on recruitment of study participants, and translating results ensure that the patient experience is a central component of our research initiatives.

Our 14 panelists include patients who themselves are medical professionals; people who are caregivers; people with various kinds of spinal CSF leak, whether iatrogenic, spontaneous, or due to CSF-venous fistula; and people both living with and in recovery from spinal CSF leak.

To date, the Panel has met regularly to review current research interests and initiatives from our medical advisory board, and has signed a letter of support for a grant application for a study that would be the first clinical trial in spontaneous intracranial hypotension. Panelists have also represented the panel at working group meetings with our medical advisors as we work towards creating a research network and patient registry.

EDS comorbidity coalition

One board member participates in this ongoing collaboration between several organizations and stakeholders.

our programs

RESEARCH

research network and patient registry

In June of 2023, the Foundation was pleased to announce that we are partnering with National Organization for Rare Disorders, Inc. (NORD) to create a registry for spinal CSF leak patients that will launch in the Spring of 2024.

We are proud to announce the development of a

Spinal CSF Leak Patient Registry

In partnership with NORD®



The National Organization for Rare Disorders is an independent nonprofit that built its IAMRARE® online registry platform as part of its mission to help identify and treat all 7,000 rare diseases. Spinal CSF Leak Foundation is a member of NORD, and together we will work to understand the challenges and identify opportunities to advance research for this rare disease patient population.

Here are just some of the crucial ways a patient registry can help us understand more about spontaneous intracranial hypotension and spinal CSF leak:

Understanding disease prevalence: While small studies have estimated the annual incidence of spontaneous intracranial hypotension to be 4 to 5 per 100,000, our understanding of disease prevalence remains unknown. The prevalence of spinal CSF leaks resulting from medical procedures is also unclear. A patient registry can help to determine the actual number of affected individuals, providing a more comprehensive understanding of the disease burden.

Facilitating research and advancements: By collecting data on patients with spinal CSF leak, a patient registry creates a valuable resource for researchers and clinicians, who can analyze the data

our programs

RESEARCH

to identify patterns, risk factors, complications, and treatment outcomes, leading to improved understanding, better therapeutic interventions, and potential breakthroughs.

Enabling collaboration and networking: Registries foster collaboration between healthcare providers, researchers, and patient communities. They create networks for sharing knowledge, expertise, and best practices, leading to improved care coordination, increased awareness, and advocacy efforts.

Empowering patients and families: A patient registry allows individuals and families to actively contribute to research and the understanding of spinal CSF leak. By participating in the registry, patients and families become advocates for their own health, gain access to support networks, and contribute to shaping research priorities and advancements.

Our patient registry with NORD's IAMRARE® online platform will be critical for promoting research, improving diagnosis and care, fostering collaboration, and empowering patients and families. It will also help address the unique challenges faced by individuals with spinal CSF leak and contribute to better outcomes and quality of life. And it will be an important part of the collaborative research network we hope to launch next year.

This network will identify and set research priorities; fund high-impact, patient-centered, multicenter research projects; and address best diagnostic practices and treatment algorithms for optimal patient outcomes to establish standards of care. Our Patient Advisory Panel for Research will be vital in ensuring the patient voice is front and center within the governance of the research network. With a network of researchers performing multi-site studies, we will be able to accelerate not just our understanding of the disease but the development of therapies and treatments that will potentially provide a cure. All of this will help us address the most persistent questions about spinal CSF leak, from diagnosis to treatment and beyond. And most importantly, it will help us make a profound, lasting, and measurable difference in patients' lives.



our programs

COMMUNITY SUPPORT & ADVOCACY

online support

Our online support community at Inspire has over 12,000 members. Inspire's robust privacy controls protect sensitive health information as people connect with one another and share their experiences.

We have a team of volunteers who act as community leaders, monitoring discussion, and participating and providing quality information as needed. This past year, our team of community leaders continued its work on creating a messaging library to help coordinate

responses and ensure that the information, links, and other helpful resources we share is accurate and up-to-date. We also formalized a process for attending to the needs of our community in a way that supports the community leaders who do such important, emotional work. With community-building plans in mind, we look forward to continuing to nurture and build a sense of togetherness within our community as it continues to grow.

email support

People reach out to the Foundation with questions or requests via email on a daily basis. Whether they are looking for physicians, specialists, or simply need to connect with someone, we respond to each email promptly—within a day in almost all cases. In tandem with supporting our Inspire team of volunteers, we have developed a response database/messaging library to assist us in replying to these email requests.



our programs

COMMUNITY SUPPORT & ADVOCACY

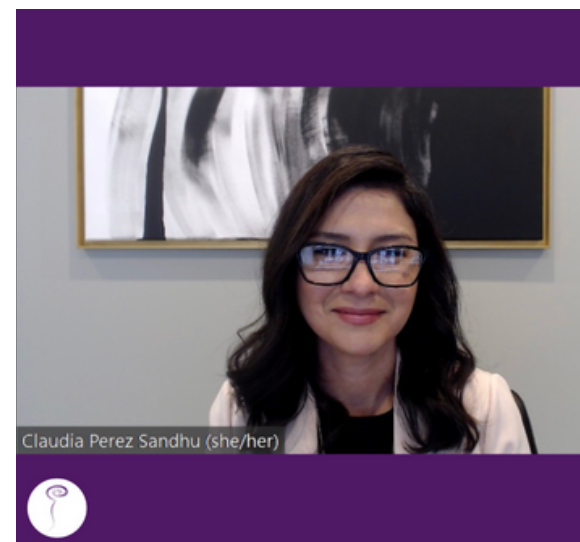
physician directory

In November 2022, we launched our public [physician directory](#), which features listings of physicians familiar with spinal CSF leak who have agreed to share their information publicly. We continue to update the directory as needed.

advocacy

We are members of Alliance for Headache Disorders Advocacy, National Organization for Rare Disorders, and Rare Foundation Alliance (Global Genes). These organizations are skilled at advocacy and provide opportunities to contribute our voices on arrange of issues relevant to intracranial hypotension patients, such as insurance, disability coverage, and research funding. We sent several advocates to Headache on the Hill, the annual advocacy event organized by the Alliance for Headache Disorders Advocacy. One of our attendees shared how [her experience as a first-time advocate gave her hope about the future](#).

Our Advocacy team has been working on several projects to help further the goals of patients being viewed as equal partners in care and having tools to advocate for their own care; physicians being educated through our advocacy work to recognize and diagnose the often complex but not necessarily rare symptoms of a spinal CSF leak with either the knowledge to treat or properly refer; and, ultimately, to make it possible for patients to receive prompt and appropriate treatment, with positive long-term outcomes.



our programs

COMMUNITY SUPPORT & ADVOCACY

advocacy

Are you a patient with Medicare coverage

who has received an epidural blood patch as treatment for SPONTANEOUS spinal CSF leak?

If so, the Spinal CSF Leak Foundation invites you to take an anonymous survey regarding your care coverage.

Take the survey at bit.ly/MED-EBP

In November 2022, we released a survey to help us understand patients' issues with medicare coverage of epidural blood patch for spontaneous spinal CSF leak. The results of this survey helped clarify which medicare contractors need guidance from the Centers for Medicare & Medicaid Services to ensure coverage, a project which is still in progress.

In February of 2023, as part of the Spinal CSF Leak Foundation's advocacy efforts, we conducted a qualitative survey of clinicians as well as patients and their care partners asking where they saw the greatest need for advocacy. The responses yielded one over-arching concern, voiced by nearly every single respondent: The

need for more trained medical professionals.

While the number of excellent clinicians and centers specializing in spinal CSF leak care has grown significantly in the last ten years, we recognize that spinal CSF leak is still under-recognized and under-diagnosed. Our goal is both to support clinicians and centers in their ongoing work, and to accelerate those efforts.

To that end, we announced a new Clinician Education Initiative. Under this initiative, clinicians and centers can apply for funding to further their education. The Foundation is looking to support projects during the 2023-2024 fiscal year that show the greatest accessibility as well as exponential potential.

CLINICIAN EDUCATION INITIATIVE

GOAL
To exponentially grow the number of clinicians who are trained to recognize, diagnose, and successfully treat spinal CSF leak in the US and across the globe.

BACKGROUND
As part of the Spinal CSF Leak Foundation's advocacy efforts, we conducted a qualitative survey of clinicians as well as patients and their care partners asking where they saw the greatest need for advocacy. The responses yielded one over-arching concern, voiced by nearly every single respondent: The need for more trained medical professionals. While the number of excellent clinicians and centers specializing in spinal CSF leak care has grown significantly in the last ten years, we recognize that spinal CSF leak is still under-recognized and under-diagnosed. Our goal is both to support clinicians and centers in their ongoing work, and to accelerate those efforts. To that end, we are pleased to announce our new Clinician Education Initiative. Under this initiative, clinicians and centers can apply for funding to further their education. The Foundation will be looking to support projects that show the greatest accessibility as well as exponential potential.

DREAM BIG
Our hope is ultimately for every clinician worldwide to know about and be able to identify spinal CSF leak, and for every hospital to offer epidural blood patching as a minimum standard of care.

INITIATIVE EXAMPLES

- A clinician wishing to receive hands-on training with a specific center can reach out to that center to make arrangements and then request travel funding from the Foundation. This is encouraged both among clinicians within and outside of the United States.
- Traveling to attend a webinar or seminar.
- Creation of training materials, including video documentation of processes and procedures as allowed within accordance of the law.
- Dream big! You tell us and let the Foundation figure out how we can assist your educational efforts.
- Funding to send an expert clinician to train others in another hospital setting.
- Hosting a webinar or seminar.

spinalcsfleak.org

2022-2023

FINANCIAL REPORT

For fiscal year ending June 30, 2023

Total Assets Beginning Fiscal Year	286,478
Total Revenue	157,715
Expenses	
Programs	82,445
Administrative	24,335
Fundraising	19,506
Total Expenses	126,286
Excess	31,429
Total Assets Year-End	317,909